

SENATE JOINT RESOLUTION 564

By Yager

A RESOLUTION to designate February 29, 2012 as “Rare Disease Day” in Tennessee.

WHEREAS, in an effort to raise awareness in the United States about rare diseases, “Rare Disease Day,” which will be observed on February 29, 2012, has been designated as the occasion to bring forth a national audience in an attempt to raise cognizance about issues surrounding rare diseases; and

WHEREAS, there are nearly 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 Americans; and

WHEREAS, while each of these diseases may affect small numbers of people, rare diseases as a group affect almost thirty million Americans; and

WHEREAS, many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

WHEREAS, while nearly 330 orphan drugs and biologics have been approved for the treatment of rare diseases affecting between eleven and fourteen million people, according to the Food and Drug Administration, more than fifteen million Americans suffer from rare diseases who have no treatment specific to their disease; and

WHEREAS, individuals and families affected by rare diseases often experience a sense of isolation, difficulty in obtaining an accurate and timely diagnosis, few treatment options, and problems related to accessing or being reimbursed for treatment; and

WHEREAS, some rare diseases, such as Lou Gehrig’s disease and Huntington’s disease, are relatively well known; many others are not known at all by the public, so that patients and their families must bear a large share of the burden for things such as raising funds for research; and

WHEREAS, the National Organization for Rare Disorders (NORD) organizes a nationwide observance of “Rare Disease Day” on February 29, and patients, medical professionals, researchers, government officials, and companies developing treatments for rare diseases are encouraged to join together to focus attention on rare diseases as a public health issue on that day; and

WHEREAS, successes of the annual Rare Disease Day USA include governors in forty states issuing proclamations recognizing the important issue, rarediseaseday.us being launched, more than 350 groups signing on as Rare Disease Day Partners, and patient stories appearing on ABC News, blogs, editorials, newspapers, and many websites to address the travailing issue; and

WHEREAS, since nearly one in ten Americans have rare diseases, thousands of residents of our great State are among those affected by rare diseases; now, therefore,

BE IT RESOLVED BY THE SENATE OF THE ONE HUNDRED SEVENTH GENERAL ASSEMBLY OF THE STATE OF TENNESSEE, THE HOUSE OF REPRESENTATIVES CONCURRING, that we join in the designation of February 29, 2012, as “Rare Disease Day,” and encourage all Tennesseans to educate themselves about the reality of rare diseases across our State and Nation.

BE IT FURTHER RESOLVED, that an appropriate copy of this resolution be prepared for presentation with this final clause omitted from such copy.